



Economic and Social Council

Distr.: General
1 April 2015

Original: English

Economic Commission for Europe

Conference of European Statisticians

Sixty-third plenary session

Geneva, 15-17 June 2015

Item 4 of the provisional agenda

Modernization of statistical production and services and managing for efficiency

Something old into something new— revitalizing vital statistics through innovation and improved efficiency

Note by the National Center for Health Statistics of the United States of America

Summary

The paper introduces the experience of the National Center for Health Statistics of the United States of America in modernizing vital statistics through innovation and improved efficiency. Now with available web-based reporting systems to hospitals, physicians, etc. the timeliness of vital statistics has been significantly improved. More efficient communication with the data providers means improved quality control. Data quality is also improved through increased use of web-based tutorials describing reporting requirements for difficult vital events to data providers. This paper will discuss these improvements and future development plans for linking electronic health records to vital events which will provide a rich, longitudinal reporting system.

The paper is presented for discussion to the second session of the Conference of European Statisticians' seminar "Modernization of statistical production and services and managing for efficiency".

GE.15-06936 (E)



* 1 5 0 6 9 3 6 *

Please recycle



I. Introduction

1. The National Vital Statistics System (NVSS) of the United States provides the nation's official vital statistics data based on the collection and registration of birth and death events at the local and state level. NVSS provides the oldest, most complete and continuous data available to public health officials at the national, state and local levels, and in the private sector. Vital statistics have been a critical component of our national health information system, allowing us to monitor progress toward achieving important health goals.

2. Examples of NVSS data include: teen births and birth rates; prenatal care and premature births; risk factors for adverse pregnancy outcomes; infant mortality rates; life expectancy and leading causes of death. It is a unique cooperative effort involving the public, local, state and federal government. NVSS has several interesting aspects:

(a) It is a census;

(b) It is based on administrative data;

(c) It is a cooperative/shared governmental responsibility based on state registration law and federal reporting requirements and standards.

3. Historically, vital statistics have been used to identify current (and emerging) health problems requiring public health action. Over the last four decades, however, time lags between vital event occurrence and statistical report release have resulted in the NVSS becoming more of a historical reporting system—valuable for illustrating trends as a nation and across communities, but not for identifying what health issues we are currently facing. Now with web-based reporting systems available to hospitals, certifying physicians, medical examiners and funeral homes, vital statistics reporting is positioned as a central component of the Center for Disease Control's (CDC) disease surveillance for chronic, infectious and injury-related mortality and high-risk births. As an example of significant change, just a few years ago, vitals data were several years old before reported. We are now receiving about 45 per cent of all vital records within 10 days of the event; soon, that will be at 80 per cent. As a result, NVSS now has the internal systems within the National Center for Health Statistics to monitor disease outbreaks on a near real-time basis. For example, NVSS can now track influenza and pneumonia deaths more quickly and completely with vital statistics than other current surveillance systems.

4. In fact, NVSS is now working with CDC epidemiologists to identify a broader range of events to track on current flow basis. With the improvement in timeliness also comes better data quality. More efficient communication with the certifying physicians and other data providers means improved quality control. Data quality is also improved through increased use of web-based tutorials describing reporting requirements for difficult vital events to data providers. In the future, we will pilot the linking of electronic health records to vital events, which provides the future possibility of a passive, longitudinal reporting system from birth to death.

5. The history of the collection of vital statistics in the United States is a window into the shared federal and state governance structure and is also one of the earliest examples of a statistical system built upon an administrative system responsibility and that is the registration of vital events. In the United States, although the constitution requires the federal government to undertake a Census, there is no mention of the federal responsibility for registration of its citizens through the registration of births. In the United States in the 18th century, vital registration was primarily a church function and then slowly began as a

governmental function in cities. In the first half of the 19th century, the information from the registration of vital events was beginning to be used for public health purposes in five cities (Boston, New York, Philadelphia, Baltimore and New Orleans) and in the early 1800's those cities contained about eight per cent of the population.

6. From a national perspective, vital statistics first began to be collected in 1850 through the decennial census. It became apparent this process was inadequate from a demographic and a public health perspective and in the beginning of the 20th century the federal government began encouraging states and cities to register vital events and to collect information in a standard manner. It was not until the mid-1930's that the United States had full coverage of vital events through state and city vital registration.

7. The United States currently has 57 vital registration areas (50 states, New York City, Washington, D.C. and 5 United States Territories). To this day, the federal government through the National Center for Health Statistics (NCHS) is authorized to collect vital statistics from the states but states are not required to provide this information to NCHS. This unusual governance structure has led to a cooperative relationship by which NCHS provides standards and funding for the collection of vital statistics data from state controlled registration systems. As such it is the longest continuous joint federal and state data collection activity in the United States.

II. Usefulness of vital statistics

8. Statistics based on births and deaths registered in the United States are a primary source of data used to track the health status of the population, to plan, implement, and evaluate health and social services for children, families, and adults, and to set health policy at the national, state, and local levels. Data on access to prenatal care, maternal risk factors, infant mortality, disparities in health status, changes in the rankings of causes of death, life expectancy, years of potential life lost, and other pregnancy and mortality indicators provide the staples for public policy and programmatic debates about improving health and health services delivery.

9. Unlike any other public health data system, the national vital statistics system provides nearly complete, continuous, and comparable federal, state, and local data to public health officials and programs. This strength enables population-based analysis and comparisons to be undertaken at the national, state, and local levels by age, race, ethnicity, and sex. For example, with approximately two and a half million deaths each year, disparities in the leading causes of death by race and age can be monitored and compared at the local, state, and national levels. Rare and emerging causes of death can be identified, and using both the underlying and contributing causes of death, the impact of such diseases as hypertension, diabetes, and atherosclerosis on mortality can be measured.

III. The problem

10. Despite the importance of the nation's vital statistics system, in the late 20th century and early 21st century, data collection and dissemination was based on outmoded vital registration practices and systems at all levels of government, a fact that raised concerns about data quality, timeliness, and the lack of real-time linkage capabilities for the more than six million annual vital events with other data systems.

This state/federal cooperative system had become so arthritic that vital events at times were reported over two years beyond the actual year of the event. Vital statistics reports became more of historical interest, indicating where we had been and not what health challenges and successes we were currently experiencing. Vital statistics, the cornerstone to public health reporting was quickly becoming irrelevant to public health intervention and practice. From a demographic perspective the late provision of current birth and death data was impacting the availability of post-censal estimates of population for states and counties. Something had to be done.

IV. The causes

11. The causes for a declining lack of timeliness and quality could be found in both systems and procedures at the federal and state level. Contributing to these causes was a lack of funding for the activities and a mind-set that annual reporting delays were an inevitable outcome of this shared cooperative federal/state activity. Some of the specific procedural causes included:

- Data were only published annually and so data were not sent in to NCHS as it was received. Much of the data was sent later in the year which delayed quality control of the data through data edits.
- Late data edits meant that questionable items were unresolved and coded accordingly.
- NCHS did not publish its annual report until all states had responded, the slowest state ruled the data release date which took pressure off of other states which could have reported earlier.
- NCHS was late in paying states for their data and that delay grew as NCHS's budget situation grew worse.
- The delay in payment to the states caused the states to delay sending their data to NCHS and also impacted the states capacity to update their IT systems.
- States had trouble maintaining qualified cause of death coding staff, ironically caused by federally developed automated mortality coding systems.
- Major increases in the data content in the 2003 revision of vital events in the United States came about without funds to states to change their systems, which in turn caused states to modify their data sets over time complicating the compilation of a national data set containing comparable data.
- For most states the reporting of deaths was paper driven. The demographic part of the death certificate was completed by the Funeral Director and the medical portion was completed by the certifying physician or Medical Examiner/Coroner. Those certificates many times were then delayed even more because they were first to a local registrar before being sent to the State Office to be put in electronic form.

12. The systems issues were significant. As noted above, the collection of death information was primarily a paper-based process, unchanged at the local and state levels for the last half century. Funeral Directors were responsible for collecting demographic information on the decedent from the next of kin, while attending physicians, medical examiners, or coroners provided the medical information on cause of death. Demographic and medical information were brought together manually by passing the paper certificate back and forth; the certificate data did not

become computerized until reaching the state vital registration office, many times after considerable delay.

13. The lack of automation at the source precluded timely follow-back to improve data quality and did not take advantage of existing internal systems of funeral directors and physicians. The Internet was not being used for electronic data transfer between data providers and state registration offices. The systems at the federal level were antiquated flat file based with little reporting back to the states and most significant editing was done at the end of the reporting year far too late for improving data quality. These systems did not provide the states adequate information on how they were doing relative to other states or on their results as compared to the required timing of the contract deliverables.

14. Although NCHS had developed an automated mortality coding system and provided it to the states for their use, as the throughput of the system improved to over 80 per cent it became harder for the states to keep qualified coders to deal with the remaining difficult to code records. Also maintaining those systems for the states in their own computing environment was cumbersome.

V. The strategy

15. Because the causes were many, the strategy to improve was many faceted. Funding was found to pay the states for their data upon receipt and passing quality control tests. A new contract was put in place not only to pay states for their data but also to improve states systems and procedures.

16. A "Good to Great" workgroup of state and federal senior staff was empowered to develop strategies to improve timeliness and data quality through joint activities. States developed more flexible web-based birth registration systems and began to develop web-based death registration systems (EDRs). States with federal support developed web-based tutorials for certifying physicians dealing with completing the death certificate. States were encouraged and began to send data to NCHS on a current flow basis instead of holding and sending batches of data.

17. NCHS systems were completely changed to more modern database structure and sent back edits immediately. Mortality coding was moved from the states to NCHS and for records coded by the automated systems, those records were sent back to the states the next day. Records requiring manual intervention at NCHS took longer but still were still available to NCHS and the states much sooner.

18. With faster data response back to the states and the states back to the data providers, hopefully data quality will improve. NCHS database systems are updated continually allowing for NCHS to consider using vitals data for not only annual reporting but also for public health surveillance.

VI. The results

19. In 2014, NCHS published for the first time final reports and accompanying data sets for births and deaths for the year 2013. In order to do this, final data for mortality for 2011, 2012 and 2013 were all made available in 2014 and 2013 birth data was made available earlier in the year than ever before.

20. The National Death Index usually running two years behind the reported data year was updated for 2014 deaths in February of 2015. Not only was final data available quicker but data were now being received from many states on a current

flow basis. For example in 2010, eight per cent of death records were received within ten days of the event. For 2014 data, over 30 per cent of records were received within ten days of the event and for 2015 almost 50 per cent of the records are being received within ten days.

21. However, currently only 36 states have EDRs and even for those states, most do not have complete coverage. The goal is to have by 2018 at least 80 per cent of all records within ten days of the event with the states NCHS is working to improve. Because of the improvement of timeliness NCHS has been working with CDC to use vital statistics for surveillance of deaths of immediate public health importance.

22. For the last year NCHS has been using vital statistics to monitor pneumonia and influenza deaths in the United States and comparing timeliness results with current reporting systems. Vital statistics reporting is almost two weeks faster. If these results continue, vital statistics could replace the old reporting system next year.

23. NCHS is also doing pilot studies for the surveillance of rare vaccine preventable disease deaths, respiratory syncytial virus (RSV) mortality and enterovirus mortality. Pilot studies will begin on suicide and disaster related mortality surveillance. Doing mortality surveillance for rare events, NCHS are not constrained to the ICD which may not be granular enough identify the event. We are now considering natural language searches on the medical "literals" provided by the physician that are used as the input to the automated medical coding system.

24. Finally from an NCHS reporting perspective we plan to report quarterly on major vital statistics indicators with the first quarterly report coming out this summer on 2015 events.

VII. The future

25. As electronic health records become ubiquitous and as their standards solidify, state based vital records systems need to take advantage of the information in these records. Initially, for births NCHS needs to see how data can be pulled from EHRs into the birth certificate to ease the provision of data from the hospitals.

26. NCHS also needs to continue studies on the validity of the birth data we are currently receiving to either modify or drop from the current standalone electronic birth records. Initially for deaths we need to see how the medical information from the electronic health records can be made available to the physicians when they are providing the cause of death information. The state-based electronic birth and health records are expensive especially for smaller states to maintain on their own.

27. NCHS is now looking at the possibility of developing a core system for states to modify and use. If and when electronic health records in the United States are not only ubiquitous but indeed become standardized to the extent that data can be shared and "understood" between different vendor systems, then perhaps the next step should be that the record that begins the electronic health records in the United States will be the birth record and the final record closing out the electronic health records would be the death record.

28. Consider the power of a longitudinal record of birth, lifetime health care delivered and death and then linked to the national interview and examination surveys which provide views of health status and health practices as well as genetic material. The future is bright.

References

"History and Organization of the Vital Statistics System". Vital Statistics of the United States, Vol.1, 1950, pp.1-19;

Rothwell, C.J. "Expansion of Scope and Usefulness of Vital Statistics", Proceeding of the 18th National Public Health Conference on Records and Statistics. DHHS Pub. No. (PHS) 81-1214, Dec 1980;

Rothwell, C.J. "Reengineering vital registration and statistics systems for the United States". Prev Chronic Dis [serial online] 2004 October, http://www.cdc.gov/pcd/issues/2004/oct/04_0074.htm;

Rothwell, C.J. "Vital Registration and Vital Statistics" Encyclopedia of the U.S. Census from the Constitution to the American Community Survey, Sage CQ Press 2011;

Rothwell, C.J., Freedman, M.A., Weed, J.A. "The National Vital Statistics System" Chapter 17 of Public Health Informatics and Information Systems, © Springer-Verlag London 2014;

Rothwell, C.J. "Challenges and Unfinished Business for NCHS and States in Vital Registration and Statistics", Presentation 2014 NAPHSIS Annual Meeting, Goggle Internet Search.